



MEASUREMENT MATTERS

DATA COLLECTION REPORT

PROJECT OVERVIEW

The Measurement Matters: Refining and Validating a PCOR Engagement Measure project (SOE-2022C2-28570) is a two-year award granted in 2023 to the LeadingAge LTSS Center at UMass Boston and Collective Insight, LLC to develop and pilot the Patient-Centered Outcomes Research Engagement Measure (PCOR-EM). Funded by the Patient-Centered Outcomes Research Institute (PCORI), the PCOR-EM was developed through a multi-phase process that included a literature scan, consensus methods meetings, focus groups, and cognitive testing interviews to identify and refine key domains and elements of meaningful patient and community partner engagement in research. Pilot data collection of the draft PCOR-EM began in April 2025 in collaboration with PCORnet® Clinical Research Networks (CRNs), the PCORI Ambassador Program, and other engaged research partners. The pilot sought valid, representative responses from individuals with direct experience in patient or community engagement, particularly in research relevant to older adults. To support expanded psychometric testing after the tool grew from 15–20 to 30 items, the final recruitment goal was increased to 300 participants, up from the original 175–225. This report summarizes the data collection strategies designed to meet that recruitment goal and documents the challenges, solutions, and limitations of these efforts.

DATA COLLECTION METHODS

Outreach and Recruitment

Our PCOR-EM outreach and recruitment process intended to reach diverse participants, including participants diverse in age, gender, race/ethnicity, education level, and engagement experience. To support outreach, the research team created the following recruitment materials:

- [Pilot Partner Outreach Flyer](#)
- [Pilot Survey Flyer](#) for potential participants
- [Frequently Asked Questions](#)
- Sample [outreach language](#) for partners

Outreach Partners

In September 2024, the research team hosted a webinar where the partnership opportunity was first presented to PCORnet® clinical research networks (CRNs). The webinar detailed the study's purpose, outreach activities, incentives, and timeline. CRNs interested in being a Pilot Outreach



Partner expressed that interest through Frontdoor. The research team also engaged a Pilot Partner Subcommittee, consisting of 8 individuals from 6 PCORnet® sites, to inform our outreach methods. The research team then collaborated with PCORnet® Frontdoor and the Pilot Partner Subcommittee to identify up to six Clinical Research Networks (CRNs) to serve as Pilot Outreach Partners. The research team conducted 6 informational meetings to familiarize Pilot Outreach Partners with the study and solicit their support. CRNs serving as Pilot Outreach Partners were offered a \$1,500 incentive for recruitment support. Due to administrative challenges for CRNs, outlined in our [Pilot Site Implementation Report](#), some CRNs did not accept the incentive, in part because of the administrative complexities associated with processing such a small payment.

Pilot Outreach Partners distributed email messages containing the Pilot Survey Flyer and survey link to individuals within their PCORnet® networks. Efforts targeted a broad range of participants across the “patient-engagement” continuum through partnerships with 3 CRNs: STAR, Greater Plains Collaborative (GPC), and REACHnet. To reach our recruitment goal, we expanded partnerships with PCORI Ambassadors, the PCORI Engagement Advisory Panel, NIH/NIA-funded initiatives, Aging Special Interest Groups, universities, and PCORI-funded projects. Outreach methods included targeted emails, listserv announcements, webinars, and conference engagement. See [Appendix A](#) for a comprehensive PCOR-EM Recruitment History report.

Screening, Consent, and Survey Administration

The pilot began with an electronic screener page outlining eligibility criteria, which required participants to be English-speaking and able to report on engagement in an engaged research project. Those who met the criteria were directed to an informed consent page that described the study’s purpose, potential risks and benefits, and investigator details. Only individuals who confirmed their consent were able to proceed to the survey.

The survey itself was administered through REDCap, a secure, web-based platform with real-time validation rules to ensure data quality. Its structure included the screener and informed consent, followed by the 30-item PCOR-EM survey, a 43-item supplemental survey, and an incentive form. To ensure accessibility, the research team offered accommodations such as a paper survey, screen reader compatibility, and recorded responses; however, no participants requested or used these accommodations during the pilot.



DATA COLLECTION CHALLENGES AND SOLUTIONS

The research team encountered several challenges during data collection that affected recruitment, participant representation, and data integrity. The team implemented targeted solutions to address each issue.

Challenge	Solution
Low yield from initial PCORnet® recruitment	Expanded eligibility to all engaged research projects; broadened outreach channels
Underrepresentation of low-engagement-experience participants	Targeted outreach to balance representation across the continuum
Fraudulent/bot responses due to public link	Added open-ended screener question; manual review; issued unique one-time links. For more details, see Appendix B: Addressing Fraudulent Survey Responses in the PCOR-EM Pilot
Risk to incentive integrity	Embedded incentive claim in REDCap after verification; cross-checked eligibility
Administrative burden	Implemented real-time fraud detection and verification workflow

DATA COLLECTION RESULTS

The PCOR-EM pilot was initiated in April 2025 and completed in July 2025, with 301 surveys collected. Although the pilot ran longer than originally planned, it stayed within the overall project timeline. The research team continually tracked progress, identified issues as they emerged, and implemented solutions to protect data quality and ensure recruitment goals were met. The most serious challenge came from fraudulent and low-quality responses when the survey link was shared outside intended networks. To address this, the team paused data collection, removed public access to the survey, and began issuing unique, one-time links only to verified individuals. A second challenge was that initial outreach through PCORnet® did not yield enough participants, leading the team to broaden recruitment to include PCORI Ambassadors, the PCORI Engagement Advisory Panel, NIH- and NIA-funded initiatives, Aging Special Interest Groups, and other engaged research partners. Finally, monitoring revealed gaps in representation, particularly among researchers with limited engagement experience. In response, the team conducted targeted outreach to balance participation across the engagement continuum.

Recruitment and Survey Completion Progress

The table below summarizes final PCOR-EM pilot survey completion. These figures reflect the number of individuals screened, found eligible, and ultimately completed the survey.



Pilot Survey Completion	
METRIC	VALUE
Screeners Completed	879
Surveys Distributed	403
Surveys Started	316
Valid Completed Surveys	301
High-quality Surveys	266

The bullets below outline how the research team defined and counted each step.

- **Screeners Completed (879):** This number represents all individuals who accessed the initial eligibility screener.
- **Surveys Distributed (403):** Only those who met the eligibility criteria on the screener were considered qualified and received a survey link. This explains why fewer surveys were distributed than the total number of screeners.
- **Surveys Started (316):** This reflects the number of eligible individuals who began answering survey questions after passing through the consent process.
- **Valid Completed Surveys (301):** A survey was considered valid if the participant met eligibility requirements, completed the PCOR-EM survey in full, and provided sufficient information to confirm participation.
- **High-Quality Surveys (266):** High-quality responses were identified using a set of predetermined criteria, including reasonable completion time, non-duplicated entries, and passing embedded attention checks. While these checks provide a useful filter, they cannot guarantee the absence of low-quality responses. It is important to acknowledge that this definition of “high quality” is operational and based on black-and-white thresholds; we cannot know with certainty the true quality of every individual response.

DATA COLLECTION LIMITATIONS

While the pilot reached its recruitment goal, several limitations in the data collection effort were experienced. Early in the process, fraudulent and automated responses came in before stronger screening measures were implemented. At the same time, strict quality controls, while necessary to protect data integrity, may have excluded some legitimate participants, e.g., those using shared devices or community internet connections. The online-only design also limited participation for individuals without reliable digital access, despite offering accommodations.



Recruitment remained uneven, with certain groups, such as researchers with limited engagement experience and those from underrepresented populations. Additional screening steps extended the pilot period, though the pilot still concluded within the overall project timeline. Finally, what we define as “high-quality” responses is based on set thresholds like completion time and attention checks, which help flag concerns but cannot fully capture the true quality of every survey. These limitations are common in online survey research, particularly when incentives are offered, and highlight the importance of careful screening and transparency in reporting.



APPENDIX A: PCOR-EM PILOT RECRUITMENT HISTORY

MEASUREMENT MATTERS

PILOT RECRUITMENT HISTORY

RECRUITMENT APPROACH

Between April 30 and July 31, 2025, we implemented a multi-pronged recruitment strategy for the PCOR-EM pilot survey. Our approach emphasized targeted outreach through established research and academic networks, professional associations, and community partners to maximize reach among patients, caregivers, researchers, and other stakeholders with engagement experience. Personalized outreach and systematic follow-up reminders were used across all channels. All outreach activities were logged in a centralized tracker documenting contacts, dates, methods (email, LinkedIn, listserv), and responses. Follow-up reminders and later outreach phases were systematically noted.

RECRUITMENT CHANNELS

The recruitment strategy relied on seven primary channels, each designed to engage specific audiences and maximize survey reach. The table below summarizes the outreach channel, timeframes, audiences reached, and key outcomes for each channel.

Channel*	Dates	Audience Reached	Key Outcomes
Measurement Matters Study Partners	Apr–Jul	Committees, advisors, internal networks	Shared via professional listservs (e.g., PVN, PPI Networks, SCRA). Summit on July 11 generated “novice-specific” language; partners re-shared flyers.
PCORI Ambassadors	Apr 30	137 Ambassadors (60 confirmed delivery)	Contacted via portal, email, and LinkedIn; asked to complete and share survey.
PCORI Engagement Advisory Panel	May 2	16 members	Direct email/LinkedIn outreach.
Listservs & Collaborative Networks	Apr–Jul	ARN (98), CEnR, STAR CRN, GPC CRN, CTSA hubs, NAPCRG	Individualized announcements and follow-ups sent. Expanded reach through national/regional networks.
PCORI-Funded Project Teams	Apr–Jun	ACTIV-6, PREVENTABLE, Chi-Ron, CONFIRM, SOE Network, 260 Engagement Award Teams	Tailored emails and reminders sent to investigators and staff. Leveraged PCORI-funded projects for peer-to-peer recruitment



Universities & Institutional Contacts	Apr–Jul	25+ universities and health systems	Engagement cores circulated screeners through institutional networks.
Conference Leads	Apr 24	9 researchers from ASA On Aging	Follow-up emails sent post-conference. Continued engagement with new contacts.

*See below for a detailed overview of each channel.

RECRUITMENT CHANNELS – DETAILED OVERVIEW

1. Measurement Matters Study Partners

Who: Subcommittee and Steering Committee members, technical advisors, internal team members

Method: Shared materials via professional listservs (PVN, PPI Networks, SCRA), personal contacts, and at the Engagement Summit

2. PCORI Ambassadors

Who was contacted: Ambassadors (137, 60 confirmed emails)

Method: Disseminated via PCORI Ambassador Portal, email, LinkedIn, with reminders

3. PCORI Engagement Advisory Panel

Who was contacted: 16 members

Method: Individual email/LinkedIn outreach

4. Listservs & Collaborative Networks

Who was contacted: Aging Research Network Listserv (98), CEnR Interest Group, STAR CRN, GPC CRN, CTSA hubs, NAPCRG

Method: Announcements distributed via email; individualized with follow-up reminders

5. Engaged Research Project Teams

Who was contacted: Investigators/staff from ACTIV-6, PREVENTABLE, Chi-Ron, CONFIRM, SOE Learning Network; 260 Engagement Award teams (2019–present)

Method: Tailored outreach emails + reminders

6. Universities & Institutional Contacts

Who was contacted:

- Stanford University – Stanford Center for Clinical and Translational Education and Research
- Boston University – BU Clinical and Translational Science Institute
- University of Missouri – Great Plains Collaborative (GPC)



- University of Kentucky – UK Community Engagement & Research Services Team
- Columbia University – Irving Institute for Clinical and Translational Research, Community Engagement Core
- University of Colorado Anschutz – Community Engagement and Population Health Research Program at NYU Langone Health’s CTSA; Engagement Studies: ROSES Study, CONFIRM Study
- University of Miami – Community and Stakeholder Engagement Team at the Miami CTSI
- University of Cincinnati / Cincinnati Children’s Hospital – Center for Clinical & Translational Science & Training
- University of New Mexico – Engage for Equity PLUS, Community Engagement Core
- University of Texas Health Science Center at San Antonio – Institute for the Integration of Medicine and Science (IIMS)
- Duke University – Clinical & Translational Science Institute, Community Engaged Research Initiative
- Penn State University – Penn State CTSI, Community Engaged Research Team
- Rockefeller University – Office of University Life and Community Engagement
- Harvard University – Harvard Catalyst, The Harvard Clinical and Translational Science Center
- Mayo Clinic – Center for Clinical and Translational Science
- University of Minnesota – CEARC (Community Engagement to Advance Research and Community Health)
- Oregon Health & Science University (OHSU) – Community Research Hub; Health Experiences Research Network
- University of Kansas Medical Center – Frontiers Clinical and Translational Science Institute, Community Engagement & Team Science
- Georgetown-Howard Universities – Center for Clinical and Translational Science
- Jefferson University (Philadelphia) – Engagement of Hispanic and Latino Families in Research (PCORI project)
- University of Pittsburgh – Development of the Self-Efficacy of Engagement Scale (CTSA connection)
- University of Virginia – Caregiver Engagement Context Study (through CTSA involvement)
- University of Massachusetts Boston – Improving Research Partnership with Engagement Mapping
- University of Nebraska Omaha – UNO Engagement Office
- University of Wisconsin–Madison – Engagement Certification listserv
- Campus Contact Connections – CC Engaged Scholars Initiative



Method: Outreach to clinical/translational science institutes and community engagement cores

7. Conference Leads

Who was contacted: 9 researchers from ASA On Aging Conference

Method: Follow-up emails post-conference

RECRUITMENT OUTCOMES

The table below highlights the main metrics used to assess recruitment efforts. Screeners Completed represents the total number of individuals who began the eligibility process. Sources Identified reflects how many of these screeners could be traced back to a recruitment source through the open-ended screener question, “Where did you hear about this study?” Surveys Distributed indicates the number of participants who met criteria and were invited via REDCap. Top Sources show the highest-yielding channels that contributed to recruitment.

Metric	Count
Screeners Completed	879
Sources Identified	748
Surveys Distributed	403
Top Sources*	Colleagues/Referrals (208), Collective Insight Contacts (194), Listservs/Partners (189), PCORI (41)

***Additional Recruitment Sources:** Project team/internal contacts, PCORI Ambassadors, PCORI Award lists, STAR & GPC Networks, CTSA hubs, CEnR Interest Group, NAPCRG, ARN Listserv, SOE Network, Subcommittee referrals, ASA conference leads, and direct invitations from PIs.



APPENDIX B: ADDRESSING FRAUDULENT SURVEY RESPONSES IN THE PCOR-EM PILOT

MEASUREMENT MATTERS ISSUE BRIEF

Addressing Fraudulent Survey Responses in the PCOR-EM Pilot

PROJECT BACKGROUND

The *Measurement Matters: Refining and Validating a PCOR Engagement Measure* project (SOE-2022C2-28570) is a two-year award granted to the LeadingAge LTSS Center @UMass Boston and Collective Insight, LLC in 2023 to develop and pilot a Patient-Centered Outcomes Research Engagement Measure (PCOR-EM). Funded by the Patient Centered Outcomes Research Institute (PCORI), the PCOR-EM was designed through a multi-phased process inclusive of consensus methods, focus groups, and cognitive testing interviews to assess meaningful patient and other community partner engagement in research. The research team partnered with PCORnet® Clinical Research Networks (CRNs) to reach individuals with direct experience in patient or community engagement to pilot the PCOR-EM. The research team then expanded outreach to other partners to increase the pilot response rate, including PCORI Ambassadors, the PCORI Engagement Advisory Panel, NIH/NIA-funded initiatives, Aging Special Interest Groups, universities, and PCORI-funded projects. Additionally, the research team expanded recruitment outside of the United States, including to Canada and the United Kingdom. Individuals who tested the PCOR-EM were offered a \$35 gift card incentive for completing the survey.

ISSUE BRIEF PURPOSE

While PCOR-EM outreach targeted specific, trusted networks, the **web-based nature of the survey** introduced vulnerabilities that allowed ineligible individuals (or possibly automated bots) to pilot the tool solely for the incentive. The research team recognized this issue within days of initiating the pilot process, and at that time, assessed root causes and solutions to mitigate the inclusion of fraudulent responses so not to undermine the validity of the PCOR-EM pilot findings and inappropriately disseminate gift card incentives. Given the growing challenge of fraudulent online survey responses, particularly when financial incentives are offered,ⁱ project advisors requested the research team document their PCOR-EM pilot experiences and lessons learned, which are highlighted in this issue brief.

EXPERIENCES AND LESSONS LEARNED

Problem Identification

The research team designed the PCOR-EM pilot survey for distribution only within networks conducting community-engaged research. Within the first days of the pilot, however, we discovered that the survey link had been shared broadly and accessed by individuals outside these networks who were not conducting or partnering in engaged research. We identified this issue through the following data characteristics:

- Duplicate names, emails, and/or IP addresses across survey responses



- Email patterns typical of fraudulent activity (e.g., name + numbers @gmail.com)
- Large batches of survey responses within minutes of each other
- Vague or implausible answers to “how did you hear about this study?”
- Numerous non-U.S. IP addresses
- Minimal completion time (less than 5 minutes)

Root Cause of the Issue

The research team held internal meetings to investigate the root cause of the fraudulent PCOR-EM survey responses and conducted brief literature and web reviews to compare our experience with others. We determined that the primary cause was linking the eligibility survey directly to the PCOR-EM survey. This design allowed anyone who passed the eligibility screener to immediately complete the full survey without additional review or verification by the research team.

SOLUTIONS IMPLEMENTED

The research team paused the survey immediately upon detection of fraudulent activity and implemented a multi-pronged verification protocol to address the large number of fraudulent responses. This multi-pronged verification protocol included 1) Controlled Survey Access, 2) Enhanced Eligibility Screening, and 3) Secure Incentive Distribution. Each of these protocol elements are described below.

Controlled Survey Access

The research team removed public access to the full survey to reduce opportunities for fraudulent entry. Instead, we created a separate screener link that allowed us to complete robust eligibility screening before granting access to the pilot survey. Once participants passed this review, we sent them a unique, one-time survey link directly to their verified email. This controlled process ensured that only eligible and authentic participants advanced to the survey stage.

Enhanced Eligibility Screening

The research team required all participants to complete a screener before they could enter the pilot survey. To strengthen verification, we added an open-ended question, “How did you hear about our study? Please be specific.” Our team manually reviewed each screener submission and applied multiple checks to determine authenticity. These checks included assessing the plausibility of the referral source, reviewing email address formats, conducting Google searches of participant names to confirm research affiliations, identifying duplicate contact information and IP addresses, and monitoring response timing and submission patterns. This process allowed us to confirm eligibility while filtering out fraudulent or suspicious entries.

Secure Incentive Distribution

The research team embedded the incentive claim link directly into the survey platform (REDCap) so participants could only access it after verification. We then cross-referenced the incentive distribution list against verified participants to ensure that only eligible individuals received the \$35 gift card. This step safeguarded resources while rewarding authentic participation.



OUTCOMES & LESSONS LEARNED

The research team successfully identified and addressed fraudulent PCOR-EM survey responses promptly, and as a result, completed the pilot process within a 3 month timeframe and initiated the PCOR-EM pilot analysis. During this process, the research team found:

- Fraudulent responses practically ceased after implementing the new screening and access measures.
- These strategies, as described above, preserved the integrity of pilot data and ensured that incentives went to individuals who had experience with engaged research.
- There is a need for proactive fraud prevention planning in all online research involving incentives to timely detect, halt, and prevent further fraudulent entries while maintaining recruitment momentum.
- While linking eligibility screening tools directly to the pilot tool appears to save time and administrative burden, it can lead to additional staff time for manual review and numerous potentially fraudulent responses and misappropriation of incentives that cannot be recovered.

Measurement Matters: Refining and Validating a PCOR Engagement Measure is funded by a Patient-Centered Outcome Research Institute Research Award (SOE-2022C2-28570).